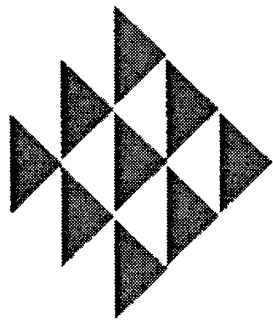


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Carers Impact Project in Hertfordshire

The Picture Now

Feedback from Carers
September 1998

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The Picture Now: feedback from Carers

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1 Improving outcomes for carers

Summary of feedback from carers

This section summarises the feedback from carers detailed in sections 2 and 3 of this paper.

Hertfordshire Action Plan	A Positive Difference	Issues to be Addressed
1 Recognition: to raise awareness of carers' needs among all professionals		Little consistency between general practices in terms of carer awareness
2 Choice: a) to ensure carer-friendly response at first contact b) to ensure carers know what help is available c) to improve carer assessments	<ul style="list-style-type: none"> ✓ First contact with Social Services had been initiated by a hospital doctor or GP ✓ Assessments had taken place promptly ✓ Social Services staff are helpful, open and sympathetic ✓ Carers felt they were properly listened to and account taken of their separate needs ✓ Carers valued Social Services staff who understood their needs and the tensions between the carer and user ✓ Assessment resulted in extra practical support and gave reassurance 	<p>Carer had repeated difficulties in contacting social services because her mother's name was 'lost' on the computer</p> <p>No-one discussed the future with carers and anticipated what would happen when caring stopped</p> <p>Carers unclear whether an assessment had taken place</p> <p>Carers poorly informed of their rights under the Carers Act</p> <p>None of the carers interviewed had received a copy of the assessment</p> <p>One negative example given of an OT assessment</p> <p>2/6 carers identified the need for better co-ordination of services</p>

Hertfordshire Action Plan	A Positive Difference	Issues to be Addressed
3 Equity: a) to ensure the needs of carers from all communities are addressed b) to ensure carers have equal access to support across the county		
4 Consultation / Involvement: to ensure carers are involved in every relevant activity of health and social services		
5 Information: to ensure all staff give good information and / or signpost carers to where they can get the information		Parent carer would have welcomed more information from her GP Carers would like more specialist expertise within general practice on specific conditions
6 Practical help: a) to improve carers opportunities for a break b) to improve care at home	✓ 5/7 carers enjoyed greater continuity of workers over the year ✓ Carers receiving 'in house' home care more confident about quality of training ✓ Charges withdrawn following reassessment (5/7 carers) ✓ Most carers very satisfied with overall quality of service	Availability of respite care in a special facility (in Stevenage) is being eroded No choice of respite Timing of respite care not easy for carers Concerns about adequacy of staff training <u>but</u> no clear explanation of the charges, nor assurance whether service would continue to be free of charge One carer's payment increased over 3 times for the same level of service <u>but</u> some reports of unsatisfactory individual workers

Hertfordshire Action Plan	A Positive Difference	Issues to be Addressed
6 Practical help: b) to improve care at home c) Other practical help	✓ Service reliable and delivered at convenient time (in the mornings) ✓ Excellent voluntary sector day centre where staff are very supportive to carer	Convenient timing in the evening more difficult to arrange Unmet needs for home care support when emergencies arise Carers concerned about changes of provider - particular worries about losing in-house homecare Taxi transport replaced following re-tendering of contracts - carer lost continuity of service
7 Emotional support: to ensure carers' feelings are respected and responded to		Lack of follow up support from some professionals as carer adjusted to life without his wife More help needed to manage transitions
8 Minimise the cost of caring: to ensure carers are fully informed of all benefits		Carer not informed of benefits until her mother was offered respite care Benefits system fails to recognise caring responsibilities as a legitimate reason for not seeking paid work
9 Co-ordinated services: a) to progress joint work with Primary Health Care Teams	✓ 4/6 carers were able to obtain prompt appointments with GP ✓ Nurses' helpline set up in one practice	Inconsistency between practices in terms of carer awareness <u>but</u> helpline of variable usefulness

Hertfordshire Action Plan	A Positive Difference	Issues to be Addressed
<p>9 Co-ordinated services:</p> <p>a) to progress joint work with Primary Health Care Teams (Cont.)</p> <p>b) to ensure carers are supported on discharge from hospital</p> <p>c) to ensure carers have input into the into the development of joint commissioning of services</p> <p>d) to improve communication between health, education and social services</p>		<p><i>Carers identified the need for:</i></p> <ul style="list-style-type: none">• More home visits for patients with chronic illness and limited mobility• More active monitoring of the condition of the person cared for• More flexible arrangements for children with special needs (e.g. extra hours available outside normal surgery hours)• Better systems for identifying carers on medical records <p>One carer considered poor liaison between health and social services, and between his wife's and his own GPs, resulted in a breakdown in his health</p>

2 Follow-up interviews with carers in Hertfordshire

Telephone interviews were conducted with a small number of carers in order to gain some current feed-back about homecare services and GP/primary care. Both services had been identified as areas of concern for carers during the earlier round of interviews and focus groups at the outset of the Carers Impact project in Hertfordshire.

a) Homecare

Seven carers were interviewed. Six were caring for their spouse and one looked after her adult son. There were four men and three women in the group. All the carers were currently in receipt of homecare. In three cases the service was provided directly by Social Services; in the remainder, the provider was a commercial agency under contract to Social Services.

All the carers had taken part in interviews or a focus group during the preliminary research undertaken by Carers Impact in Hertfordshire. The follow-up interviews sought to discover whether their experiences of homecare had changed over the intervening year.

Key issues to emerge from the interviews were:

➔ *Charging policies*

Five carers who had previously been paying for homecare, at weekly rates ranging from £6.70 to £23 per week, had had the charges withdrawn during the past year following a reassessment of their financial circumstances. While this had brought a welcome easing of restricted budgets, none of the carers had been given a clear explanation of the changes or an assurance about whether the service would continue to be provided free of charge in the future. Not everyone had benefited from the revised policy on charging. One carer reported that his weekly payment had increased sharply during the year from £50 to £193 for the same level of service. Although willing to pay for homecare, he felt that the hike in charges had been unreasonable and had written to his MP and to the Chair of Social Services to complain.

➔ *Levels of staff turnover*

Concern about the rapid turnover of homecare staff, particularly in commercial agencies, had featured strongly in the earlier discussions with carers in Hertfordshire. Although the problem had not eased for one carer, five considered that they had enjoyed greater continuity of workers over the year and one said that continuity had remained roughly the same. One

carer reported that the improvement had come about as a result of a change in provider. This was someone who was now receiving homecare direct from Social Services following a 'horrendous' experience of a commercial agency which had included a constant turnover of workers. The improvement for the other carers appeared to have stemmed from efforts by the providers to provide greater consistency of support. Where the support needs were modest, just one or two regular workers were involved. Complex care needs appeared to be covered by assigning a core of regular workers within a larger team.

➡ **Staff training**

Concerns about the adequacy of staff training surfaced once again and were focused upon the commercial homecare agencies. Some carers doubted whether new workers received any training at all since they seemed entirely unprepared when they arrived in the home, in some cases not knowing how to push a wheelchair or use a hoist. One carer said that he thought the workers were instructed about what they could and could not do but were otherwise left to get on with the job. The two carers who were receiving 'in house' homecare from Social Services were considerably more confident about the quality of training provided for staff.. One who had had both good and bad experiences of commercial providers in the past felt that the superior training and better employment conditions for Social Services staff resulted in a markedly more professional and caring service. However, the other remarked that although their initial training was good, it was not always followed through in practice because of a general lack of supervision.

➡ **Quality of individual workers**

Although most carers were satisfied or even delighted with the overall quality of the service they received, several said that it was marred by individual workers with a poor attitude. Arriving late, leaving early and doing the minimum while in the home were the main problems noted. One carer remembered a worker who began by shaving 5 minutes off her allocated hour and then gradually more and more until she was spending only 30 minutes in the home. When faced with such a situation, carers felt that nothing would be done unless they complained since there was little proactive supervision by homecare managers. While managers had proved responsive when complaints were made, the carers disliked having to take the initiative in identifying unsatisfactory staff.

➡ **Reliability, flexibility and convenience**

The morning routine of getting the cared-for person up, washed or bathed, dressed and breakfasted was often the heaviest part of the carer's day when the support of the homecare staff was most vital. The carers gave good marks to their homecare providers for delivering the service reliably and at a convenient time. One woman had requested a homecare visit at 6.45 am and, after some initial difficulty, the agency had located a worker who was able to accommodate her.

Arranging convenient homecare in the evening proved more difficult. The same carer who received the 6.45am call had been offered a night-time call at 6.15 which she and her husband considered far too early for his bed-time routine. She and the agency had eventually settled on 8.30 - 9.00pm; although this was still too early, the carer felt that the morning arrangement was too important for her to risk jeopardising it by complaining. Another carer had been told that no calls were available from the in-house Social Services homecare after 6.15pm and had decided to make a private arrangement for the evening.

➡ **Emergency support**

Several carers expressed an unmet need for homecare support when emergencies arose in the home - 'homecare on the hop' as one put it. The physical needs of the people they cared for were often unpredictable - particularly in relation to toileting - and they frequently had no alternative during the day but to attempt to lift and manoeuvre on their own. This posed a risk to themselves and to the cared-for person. Although they recognised that the logistics would be difficult for the providers, being able to summon a homecare worker when the need arose was their ideal solution. Another kind of emergency was identified where the carer was suddenly unable to care for a short period because of illness or bereavement. Once again, it had proved difficult to find the necessary homecare cover.

➡ **Changes of provider**

Some carers had experienced a sudden change of homecare provider in the past following the re-negotiation of contracts by Social Services. Where a good relationship had been established with the original workers, the sudden loss of continuity could be distressing, particularly if the standard of care offered by the new provider was inferior. Several carers referred to a recent communication from Social Services which indicated an extension of the contracting out of homecare. Although they had been assured that standards would be maintained, they remained unconvinced. The carers

currently receiving in-house Social Services homecare were particularly concerned about loss of quality.

b) GP/Primary Care

Six carers were interviewed, one of whom also took part in the homecare survey. Four were looking after a spouse or partner, one was caring for a child with physical and learning disabilities and one was supporting an adult son with mental health problems who was currently receiving hospital care. Four had the same GP as the person they cared for, one had a different GP within the same practice, and one saw a GP from a different practice.

All the carers had visited their GP with health problems of their own during the past year. Some visits had been prompted by problems that were related to caring, notably muscular injuries and emotional strain. All the people cared for, with the exception of the person in long-term hospital care, had also visited their GP.

When asked whether the service offered by the GP and practice had changed for better or for worse during the past year, half the carers could identify no change, two said that there had been an improvement, and one considered that it had deteriorated.

Key issues to emerge from the interviews were :

➡ Access to the GP

Most of the carers said that they and the person cared for were able to obtain prompt appointments with the doctor of their choice when needed. Two, however, reported difficulties. One recalled how he had had to wait 7 days in order to see a specific doctor the last time, and the other said it was increasingly difficult to get past the receptionist without giving her a detailed description of the illness and his reasons for wishing to see the doctor urgently. He objected to having to disclose such confidential information to a non-medical member of the practice.

➡ Carer awareness on the part of the GP and practice staff

As in the earlier research, the carers' accounts indicated very little consistency between practices in terms of carer awareness among GPs and primary care staff. An important indicator from the carers' point of view was the willingness of the GP to make home visits. The best experience was related by a carer whose GP made regular monthly visits to see his wife at home and who was positively encouraged to call out the GP in an emergency rather than attempt a tiring journey to the surgery. On the odd

occasion that he did call at the surgery to make an appointment, he was recognised by the receptionists and fitted into the current day's appointment schedule without question. At the other extreme was a carer who had repeatedly requested and been refused home visits for his wife and who felt that he had been cold-shouldered by his practice because of the frequency of the help he needed to cope with her physical symptoms. At one stage he had been referred for counselling which, in his view, was an inappropriate response to the circumstances which he faced. Between these extremes, the balance was towards a rather poor level of carer awareness, with GPs and practice staff paying lip service to carers' problems rather than taking positive steps to help.

➔ ***Information and advice***

Beyond seeking help with immediate medical problems, most of the carers had not turned to their GP for information or advice during the previous year. In many cases this was because they felt themselves to be familiar with the cared-for person's condition and had built up a stable pattern of services. The situation of the parent carer, however, was rather more fluid and she would have welcomed more information about the availability of nursing care in the home as her daughter grew older and heavier, and about methods of coping with continence problems. The same carer mentioned a nurses' helpline which had been set up in her practice over the past year; while she welcomed this new resource in principle, she had found that it was of variable usefulness in practice since the nurses had not always been able to identify the source of the problem which was causing her concern.

➔ ***Needed improvements***

The carers wanted to see a number of changes which would improve the quality of the support offered by GPs and practice staff. Regular home visits for patients with chronic illnesses and limited mobility was one priority. Linked to this was a perceived need for more active monitoring by the GP of the condition of the person cared for; where severe mental health problems were involved, this might necessitate the GP actively pursuing the patient in order to enforce an agreed medication regime. The parent of a child with special needs felt that her situation would be eased by the provision of transport to take her child to the surgery in an emergency without the need to pre-book. She also suggested making extra hours available outside normal surgery hours for patients such as her daughter. More specialist expertise within the practice on specific conditions would be welcomed by carers. Better systems for 'flagging up' carers on medical records was another suggestion.

c) Assessments

Face-to-face interviews were carried out with six carers who were identified for-us by Social Services as having recently taken part in a community care assessment procedure. One had been interviewed during the preliminary stage of Carers Impact's work in Hertfordshire; the others were new contacts. A before-and-after comparison of individual experiences is not therefore possible in most cases; nonetheless, the new material does offer an opportunity to compare the general patterns emerging at the two stages.

The carers and who they cared for

The interview group contained one man and five women. They ranged in age from 42 years to 84 years. Two were spouse carers and four were looking after elderly parents. Four lived in the same household as the person they cared for, one lived a short distance away and, in one case, the person cared for had recently been admitted to residential care. The periods spent caring ranged from 16 years to just over six months. All considered themselves the main or only carer for the person concerned, although most said that members of the family visited and, in some cases, gave hands-on help with caring tasks. Three of the people cared for required total personal care and were wheelchair or bed-bound; one man in the early stages of Alzheimer's disease required constant supervision and some physical help; two were capable of performing some tasks for themselves but needed a degree of practical and emotional support.

Key findings were:

➡ ***Carers still find it difficult to recognise whether an assessment has taken place***

A striking feature of the earlier research in Hertfordshire was that many carers were unclear about whether they had taken part in a community care assessment, although they were able to recall meetings with Social Services staff in which their circumstances were reviewed. This haziness in carers' recognition of assessment as a formal procedure has persisted in the follow-up interviews. Only one seemed to be familiar with the term; the others did not remember it having been applied by professionals to any of their discussions. For the purposes of our own analysis, we use the term here to describe a meeting with Social Services staff in which the situation of the person cared for and/or the carer was discussed with a view to providing or adjusting support services. Some of the carers had experienced a sequence of such meetings while, for others, it was a one-off event.

➡ ***Carers remain poorly informed of their rights under the Carers - (Recognition and Services) Act***

None of those interviewed was aware of their right to a separate assessment under the Carers Act. Indeed, none was aware of the Act itself.

➡ ***Carers are not receiving copies of written records of assessments***

Some of the carers remembered the person undertaking the assessment as having taken extensive notes during the meeting, and therefore assumed that there had been a written record. Others were uncertain about whether a record had been made. Either way, none of the carers remembered having received a copy. In the absence of a record which they shared, the carers were unable to say whether their own needs had been recorded separately from the person cared for. The carers appeared to have no expectations of receiving reports of meetings or written feed-back on the actions agreed.

➡ ***Assessments take place promptly, and doctors appear to be a key figures in initiating them***

A positive finding, in view of Hertfordshire's concern to promote carer awareness within the medical profession, was two thirds of the carers reported that their first contact with Social Services had been initiated by a hospital doctor or GP. Two carers said that their doctors had been shocked at the lack of support they were receiving and had insisted on contacting Social Services; another remembered being referred to a hospital social worker while his wife was still an in-patient; and the fourth, who had already identified a need for Social Services support, saw her GP as the gateway for making contact.

Those carers who were not referred by their GP had made contact with Social Services when their need for respite care or holiday cover in the home had become evident.

Once the contact with Social Services had been made, either directly or through a doctor, the meeting with someone from Social Services took place promptly- within days in one case and within two weeks at the outside.

➡ ***Carers describe their discussions with Social Services staff as - helpful, open and sympathetic***

Echoing the experiences of those interviewed earlier in Hertfordshire, these carers made many positive comments about the attitudes and demeanour of Social Services staff who had undertaken assessments. Typical comments were, *"A nice person - really helpful"*; *"Very easy - she's supportive and understands the difficulties"*.

In most cases, the assessments had taken place at home and had involved just a social worker, the carer and the person cared for. The carers reported no difficulty in talking to the social worker in the presence of the person cared for and several commented that they would have been uncomfortable otherwise. They found the meetings relaxed and informal, likening them to a friendly chat rather than an interview. Two carers had experience of meetings outside the home - in hospital and in a residential home - but once again had found the approach friendly.

Only one carer reported a negative interaction during an assessment. This involved an Occupational Therapist who had become involved for a brief period alongside a regular social worker when his wife was discharged from hospital. Both he and his wife resented the OT's domineering attitude and her desire to turn their home into a hospital environment. At one point she threatened to have home care withdrawn unless the wife's bed was raised to an acceptable height. The experience had been so unpleasant that the carer had decided never to admit an OT to his home again. However, he and his wife had an excellent relationship with the social worker.

➡ ***Carers feel that Social Services staff are sensitive to their needs***

Despite the lack of an explicit focus on recording their needs, the carers considered that they were properly listened to during the assessments and able to raise the issues which were most important to them. Almost all felt that the discussions had taken into account their own needs as well as those of the person they cared for. One said, *"Until I had contact with (social worker), I thought support was just for Mum. Since she's been in touch, I've realised that the support is for me too"*. Another recalled that the social worker had been keen for her to have more help than she herself was willing to accept. Support did not revolve exclusively around practical help; two carers reported that their social workers had helped them to plan for the future and to confront the difficult option of permanent residential care for the person cared for. One carer felt slightly more ambivalent than the others about the extent to which his own needs were recognised. Although his social worker was helpful and ready to make practical suggestions when needs were identified, his underlying feeling was that,

"Nobody cares about how I am unless I run into trouble". In other words, he felt valued as a carer but not as an individual.

➡ ***Carers are aware of tensions between their own needs and those of the people they care for***

Two thirds of the carers considered that there were marked tensions between their own needs for support and the wishes of those they cared for. In three cases, they were caring for elderly parents who did not recognise the need for outside help, wishing to be cared for exclusively by their daughters. The older people were resentful of the specific solutions suggested, whether these involved someone coming into the home to assist with their care or spells of respite care outside the home. The disagreements created a sense of conflict and guilt for the carer, one remarking that it was especially difficult because she came from a generation which was not accustomed to questioning parents' views .

In this predicament, the carers valued the involvement of Social Services staff who understood their own needs and interpreted them to those they cared for. They also offered encouragement and reassurance when the cared for person was introduced to a new service. For example, a reluctant day care attender was beguiled by the friendly and enthusiastic approach of the transport driver.

➡ ***More carers report that assessments are useful to them***

Assessment had resulted in extra practical support in all cases. This contrasts with the findings of the earlier research where only a minority of carers reported tangible benefits. Equipment, homecare, bath care, meals-on-wheels, respite care and holiday cover in the home had been variously added. Several carers described how the support had been adjusted over subsequent assessments in order to take into account changing needs. Better information about benefits had in some cases been a spin-off from the financial assessments that had been undertaken before key services were put in place. One carer said that the extra benefits she was now receiving had enabled her to purchase help in the home for cleaning and ironing which had freed her to pursue hobbies which she enjoyed.

The carers also identified less tangible benefits of assessment such as an easing of anxiety, and a sense of reassurance that someone was helping them in the background. One said, *"It has also made me realise that social workers are there for very ordinary situations"*.

➡ ***Some carers would like to see better co-ordination of different services within the assessment process***

Most carers felt that their experience of assessment had been satisfactory and were unable to suggest any improvements. Two, however, identified the need for better co-ordination between different services within the assessment process. One of these carers said that the contribution of Health had not been properly identified in her situation. The other commented that although assessment had given him access to different services, he still had to make separate contacts with these services when problems arose. This was difficult and time-consuming, and he would have welcomed a central contact point through which problems could be filtered.

In summary

There are evident dangers in extrapolating from a very small interview base. However, if the experiences of this small number of carers is an accurate reflection of the wider picture, it would appear that the strengths and weaknesses of the assessment process in Hertfordshire have persisted over time. Assessments are conducted in a manner which is sympathetic to carers and which takes account of their separate needs. Moreover, the process is helpful in mediating tensions between the carers' needs and those of the people they care for. More carers are identifying positive outcomes from assessment in the form of practical and emotional support.

Weaknesses are the lack of clear signalling to carers of what an assessment is and when it is taking place. Linked to this is poor practice in sharing written records of meetings and providing formal confirmation of agreed decisions. Carers remain woefully ill-informed of their rights under the Carers Act. Although carers approve of the relaxed and informal approach which Social Services staff bring to the assessment process, there is undoubtedly a need for it to be underpinned by a clearer framework of rights and expectations.

3 Carers Review of Progress

A focus group was convened to help Carers Impact assess Hertfordshire's progress in implementing its carers action plan. Three carers attended, each of whom had participated in a focus group during the preliminary research. This was useful in giving a 'before and after' perspective on developments in Hertfordshire.

The carers were invited to concentrate on those areas of the action plan of which they had recent experience (i.e. during the past year).

This produced 7 discussion topics. In practice, it was not always possible to confine the discussion to a specific time-frame, and some of the points made were general observations rather than reports of recent changes.

a) Social Services Recording Systems

One carer had been pleased when a contact with Social Services during the past year had resulted in two weeks' respite care for her mother. However, when she rang up to enquire about more respite, she discovered that her mother's name had been 'lost' on the computer. She was given a new client services number but, on trying to use it in order to reactivate the process, discovered that her mother had been 'lost' once again. She considered that this had added an unnecessary element of stress to her search for respite care.

b) Access to respite care

A parent carer said that while services for her son had remained more or less on an even keel during the past year, the availability of respite care in a special facility in Stevenage was gradually being eroded. The unit offered separate facilities for adults and children and, as the children grew up and moved into the adult category, they took their entitlement with them. Over time, this had resulted in less choice for the remaining children and their parents who were now having to fit their respite stays into a three month slot, having formerly been offered the choice of a six-month period. The other carers echoed the experience of having to fit in with whatever respite was available, rather than being able to exercise an open choice.

Another carer considered that poor liaison between health and social services and, more particularly, between his wife's and his own GPs, had resulted in a breakdown in his own health. Respite care was then offered on an emergency basis but he felt that the crisis could have been averted if the key professionals had believed what he was telling them about his inability to cope and if they had collaborated to find a solution at an earlier stage.

The carers had found that the timing of respite care did not make it easy for them to get away on holiday. Since both holiday bookings and respite bookings tended to run from week-end to week-end, the tasks of transporting and settling in the person cared for often clashed with their own last-minute preparations. The option of a mid-week start for respite care would have offered them a valuable breathing space.

One carer had received overlapping bills for respite and day care from the same facility. Apparently the different elements of care had been charged from two different budgets even though the care had been provided at the same place.

c) Follow up of ex-carers

A recently bereaved carer was dismayed at the lack of follow-up support from professionals as he adjusted to a life without his wife and without the substantial responsibilities of caring.

The carers also said that no-one discussed the future with them while they were still caring, including what would happen when caring stopped. They wanted key professionals, such as GPs, to set aside time to help them manage these important transitions, without making them feel that their were off-loading their caring responsibilities.

d) Support from the GP

While one carer felt that her GP did offer recognition and support for her role in caring for her son, the others considered that their doctors had little time or inclination to discuss their caring responsibilities. These GPs tended to respond only when an issue was brought to their attention, usually during a crisis. On one such occasion, a carer had received a helpful response from her GP in her efforts to arrange respite care but had found that there was no follow up of the matter on her next visit. It was as if the 'symptom' had been treated and then forgotten. The carers commented that there were few leaflets for carers on display at their surgeries.

e) Transport

A carer who relied on taxi transport to take her son to school in London reported that the excellent firm she had been using had been replaced following a re-tendering of the contracts with the County Council. An important element of continuity for her child had therefore been broken. She suspected that the decision had been made on financial grounds alone, without due regard to quality of service, and that winning firms had cut

corners in order to put in competitive bids. She had no contact with the new firm until the night before her son's first journey and even then had had to ring them.

f) Day care

One carer gave a glowing account of a voluntary sector day centre which her mother had begun to attend during the year. It offered an attractive environment and was run by an understanding person who offered the carer a shoulder to cry on as well as first-class care for her mother.

g) Benefits

One carer noted that certain benefits came through only after her mother had been offered respite care, the claim presumably activated by Social Services in order to produce the resources to pay for the care. The carers view was that if she was entitled to these benefits, she should have been informed about them earlier regardless of her use of services.

Another referred to the failure within the benefits system to recognise caring responsibilities as a legitimate reason for not seeking paid work. This robbed carers of their dignity and subjected them to unnecessary pressures while claiming benefit.

Top priorities for change

The carers were asked about the three most important changes they would like to see in Hertfordshire.

- ➡ Improved attitudes to carers and willingness to communicate with them across all services. Carers deserve respect and acknowledgement for their contribution.
- ➡ More respite choices and greater flexibility.
- ➡ Carers to be informed about options, including financial options, for the future, enabling them to plan. They also need to understand the implications of major policy changes, such as the privatisation of residential homes formerly run by the Council.

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